

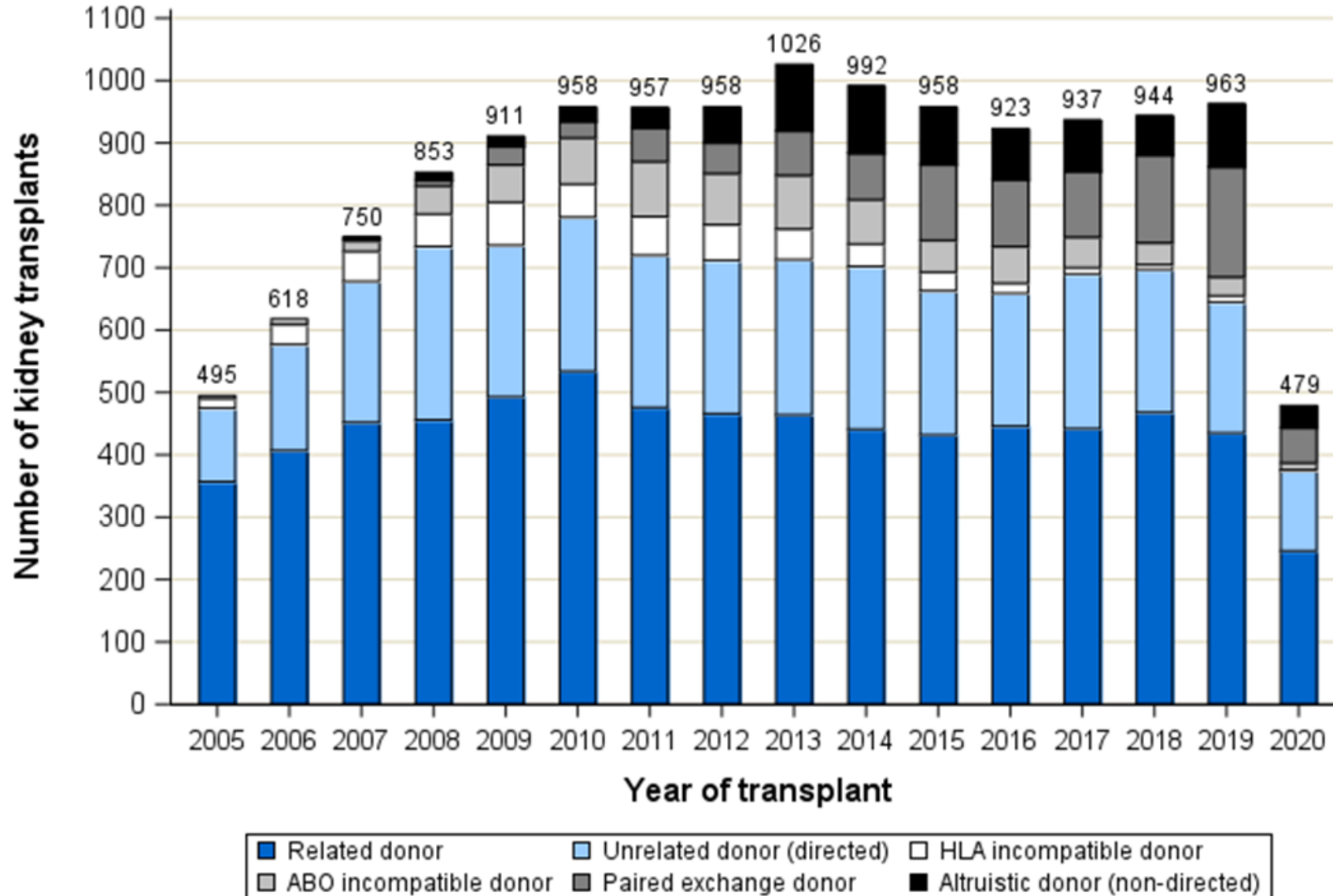
A thick blue wavy line that spans the width of the slide, starting from the left edge and ending at the right edge, with a slight dip in the middle.

Horizon Scanning: Living Donation

Lisa Burnapp

UK LKD Network Meeting, March 2021

Adult living donor kidney transplants



In 2020

Living donor kidney
transplants at 50%
compared to 2019

2/4 UKLKSS matching
runs performed

Looking Ahead



Overview

- The Next Organ Donation and Transplantation Strategy
- Living Donor Digital Transformation
- The UK LKD Network
- Saying 'thank you' to living donors

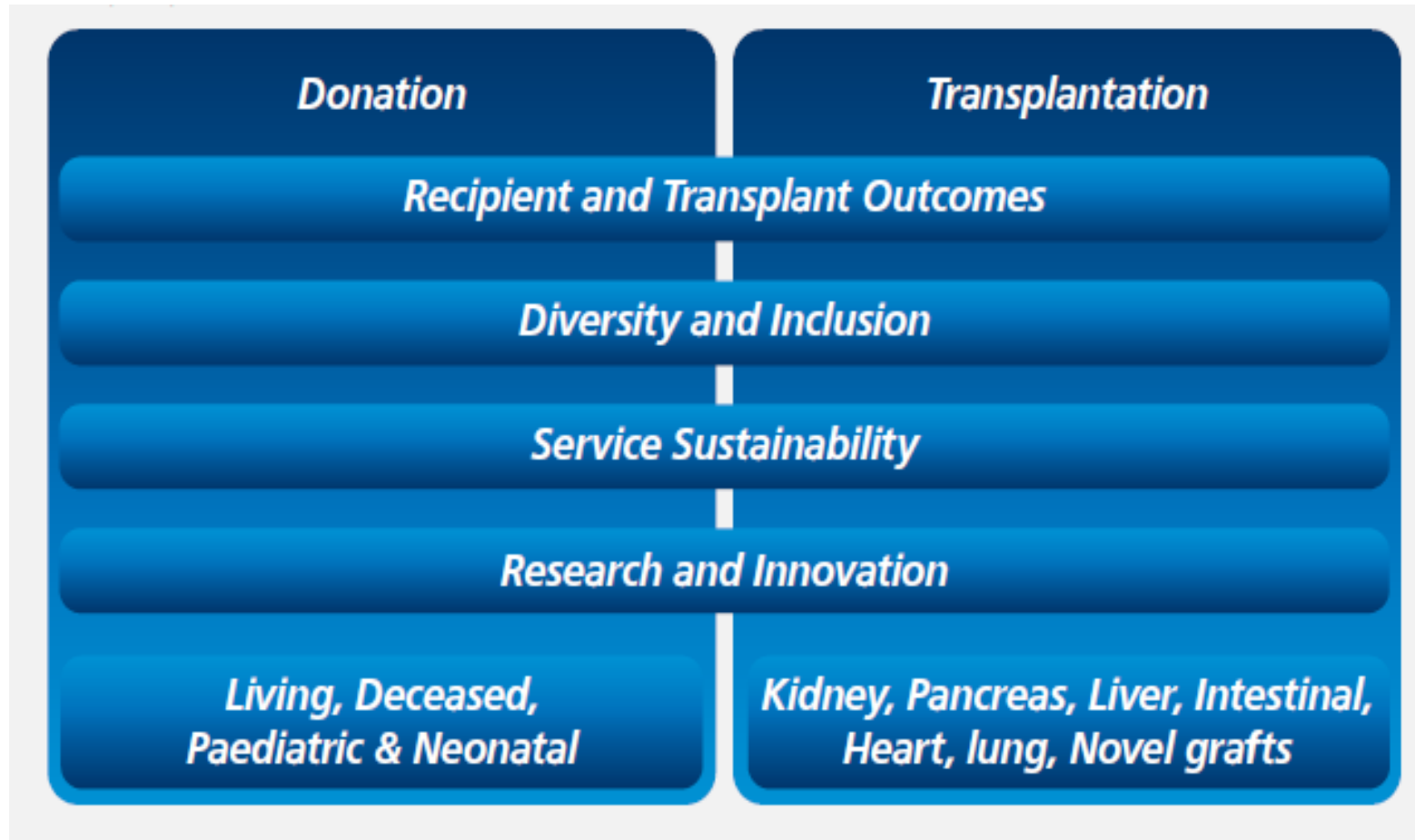
The Next Strategy

Organ Donation and Transplantation: Meeting the Need

- A UK strategy
- Builds on the success of the 2020 strategies
 - Taking Organ Transplantation to 2020
 - Living Donor Kidney Transplantation 2020
- 10-year plan
- Combines living and deceased donation
- ‘Evolution and Revolution’



The Approach



Living Donation will become an expected part of care, where clinically appropriate, for all in society



Living Donation

	Action
1.	Maximise transplant opportunities in the UK through the UKLKSS
2.	Ensure that the option of ‘transplant first’ is considered for all suitable kidney recipients, especially pre-emptive transplantation
3.	Make it as easy as possible to give or receive a living donor kidney or lobe of liver by removing unwarranted barriers to donation
4.	Promote public and patient awareness and engagement in living donation across all sectors of society and develop the ‘Living Transplant Initiative’
5.	Address unwarranted variation in clinical practice by strengthening leadership and providing clear policies and guidelines
6.	Ensure that the experience, safety and welfare of living donor transplantation is the best it can be for all donors and recipients and that donors are recognised for their gift of donation
7.	Use innovative solutions to offer more recipients the option of a living donor transplant (e.g. antibody depletion techniques)

- **Maximise transplant opportunities** in the UKLKSS
- **Use innovative antibody depletion** solutions to facilitate transplants for recipients who are not transplanted through the UKLKSS

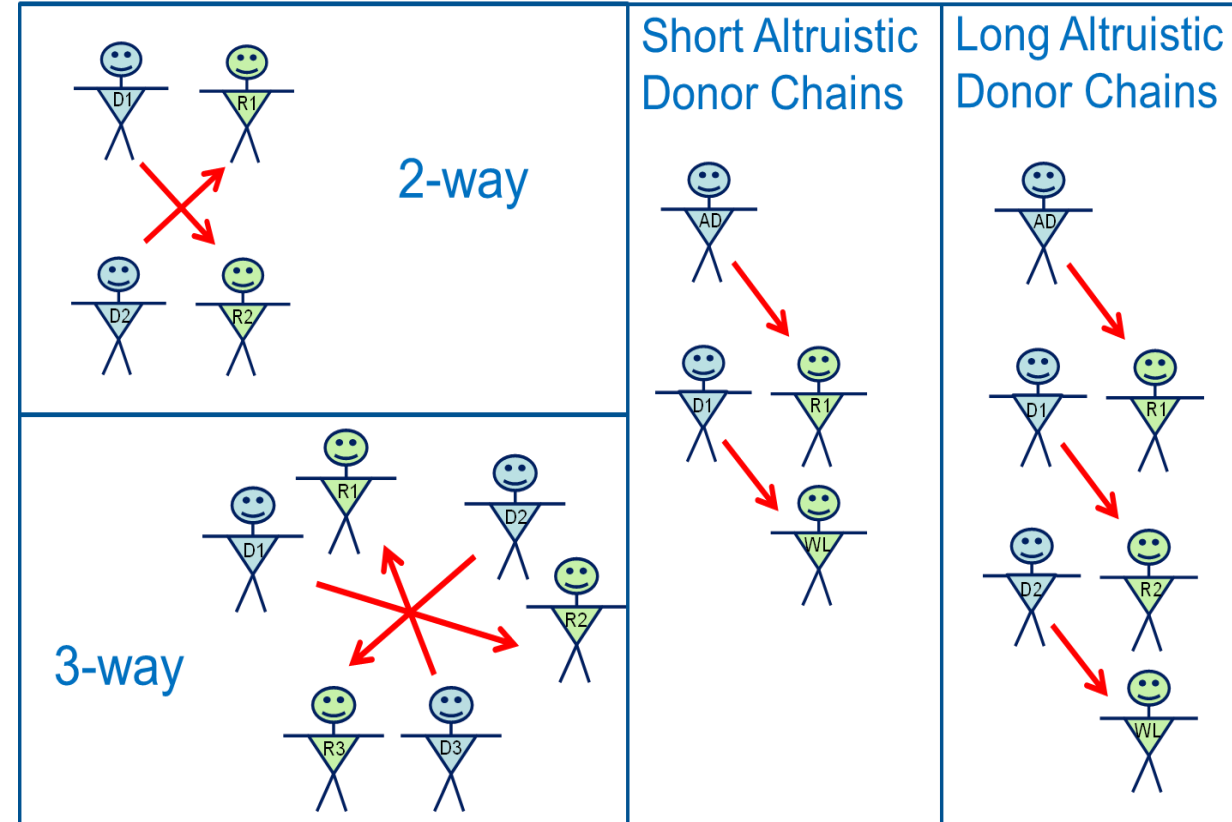
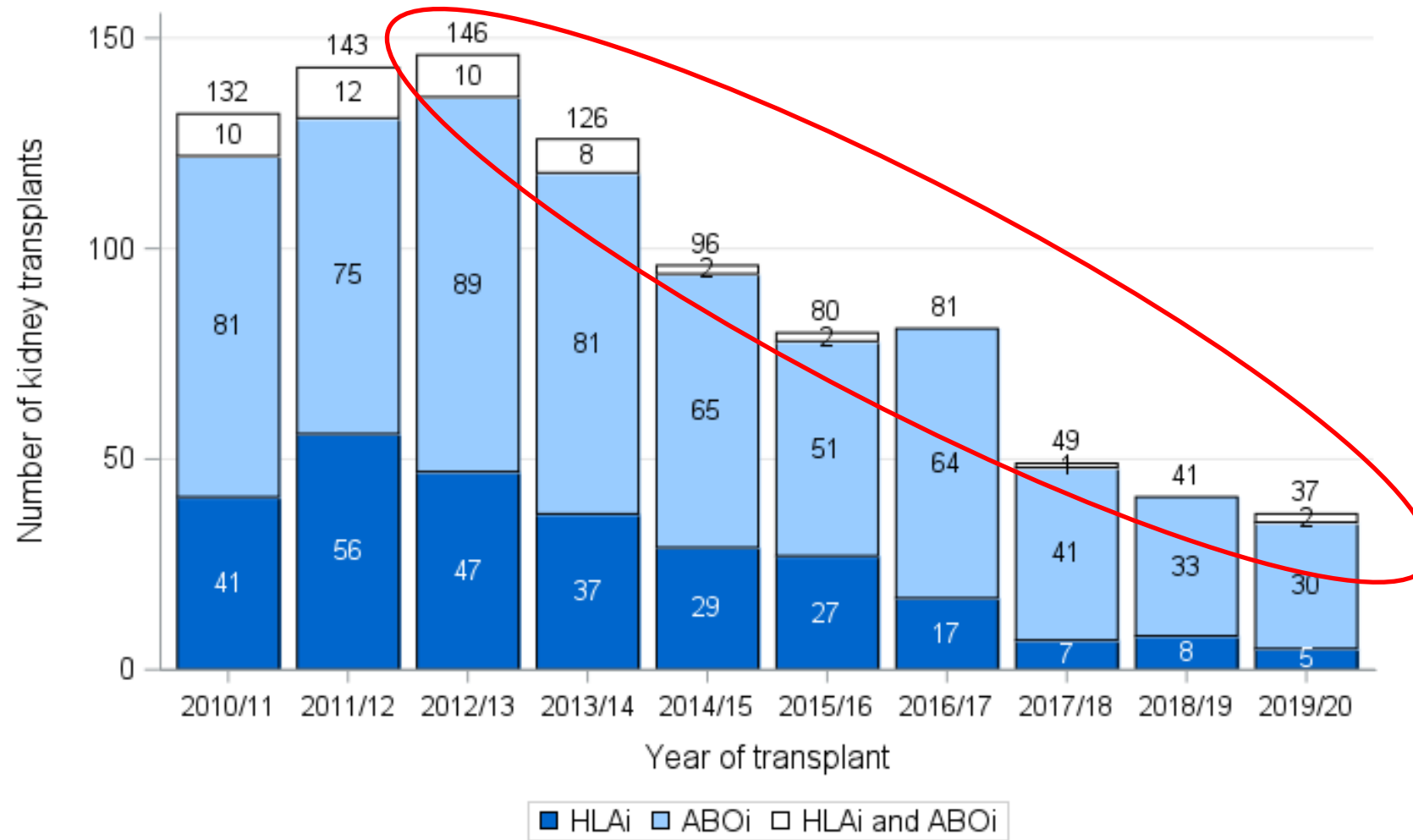


Figure 5.2 Adult living donor antibody incompatible kidney transplants in the UK, 1 April 2010 - 31 March 2020

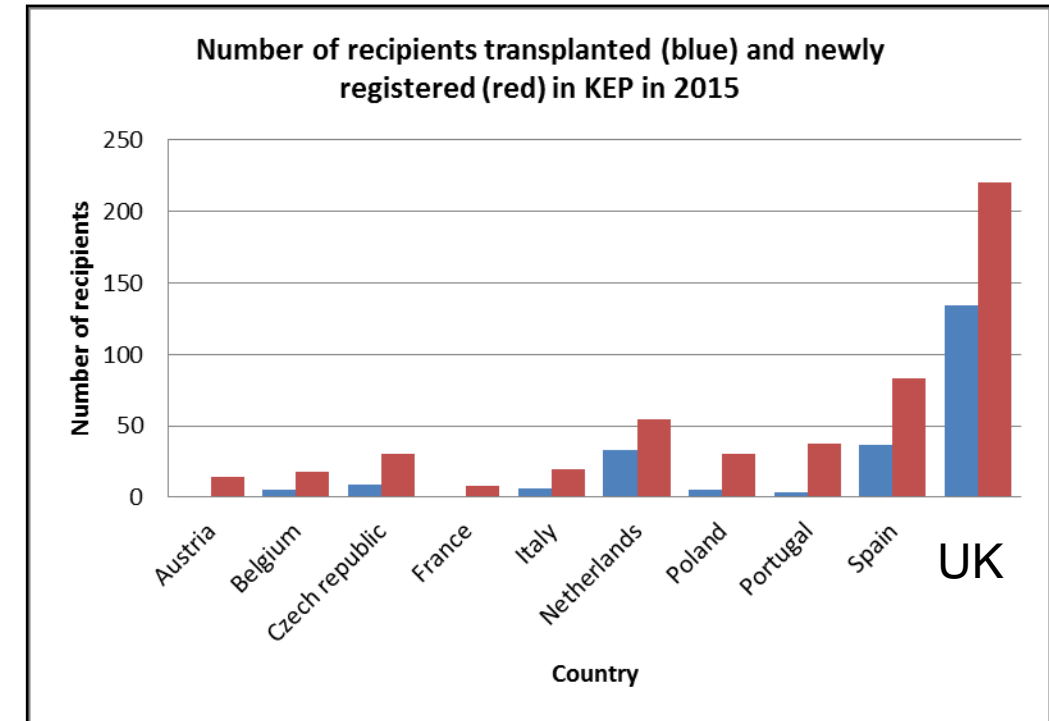
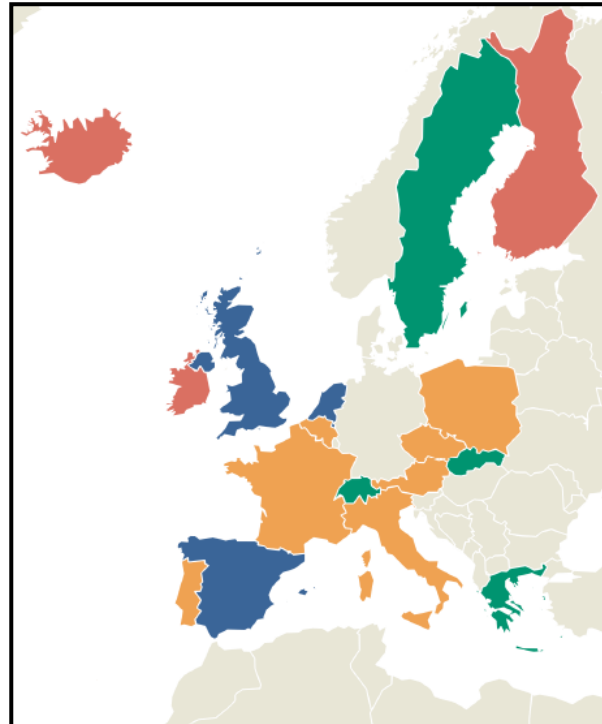


International Collaborations



European Network for Collaboration on Kidney Exchange Programmes (ENCKEP)

- Large, advanced programmes
- New, smaller programmes
- Programmes in development
- Countries with no programme



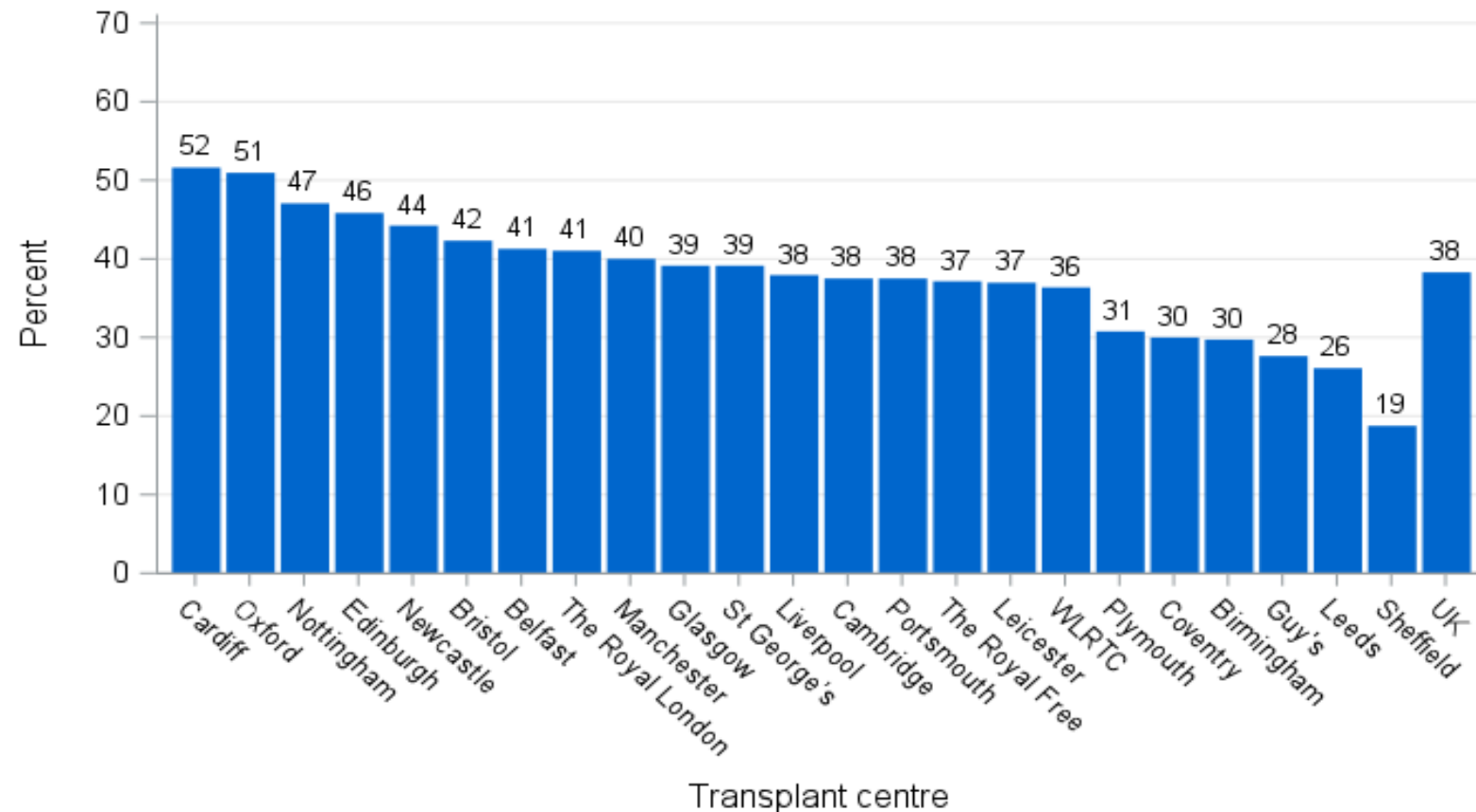
Transplantation

Building kidney exchange programmes in Europe - An overview of exchange practice and activities

Biró, P. et al. (2018) Building kidney exchange programmes in Europe - An overview of exchange practice and activities. *Transplantation*, (doi:[10.1097/TP.0000000000002432](https://doi.org/10.1097/TP.0000000000002432)) (PMID:[30247314](https://pubmed.ncbi.nlm.nih.gov/30247314/)) (Early Online Publication)

'Transplant First' for Suitable Recipients

Figure 3.8 Adult living donor pre-emptive transplant rates by centre,
1 April 2019 - 31 March 2020



- **Promote public and patient awareness and engagement in living donation across all sectors of society and develop the Living Transplant Initiative**

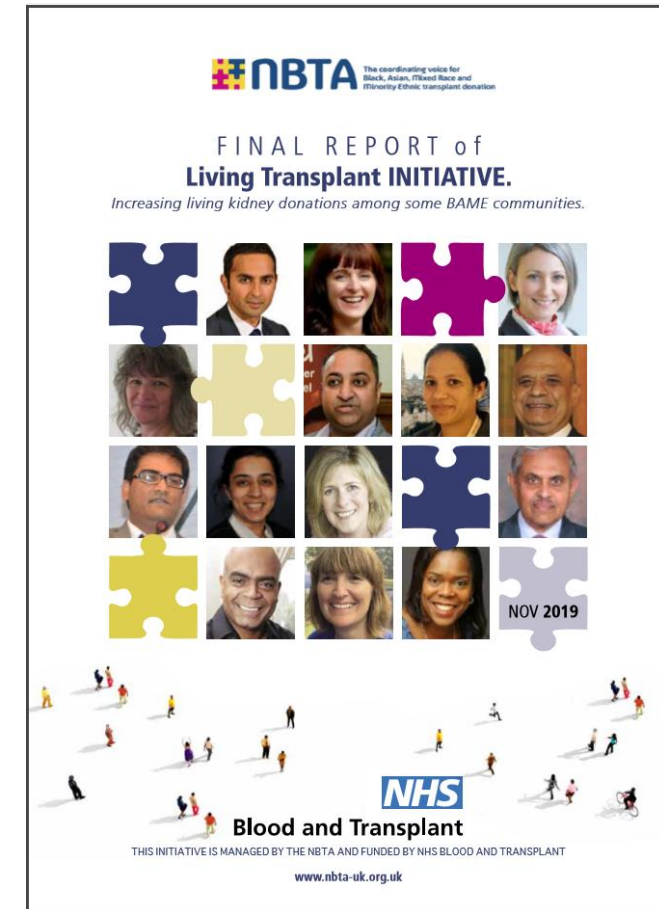
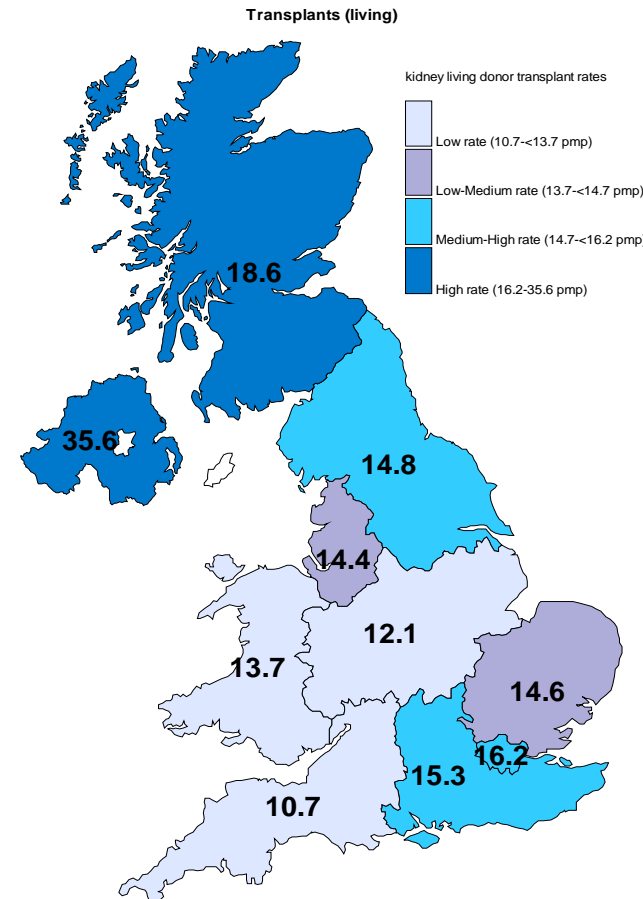


Figure 2.7 Living donor kidney transplant rates (pmp) by recipient country/NHS region of residence

- Addressing unexplained variation
- Removing unwarranted barriers to living donation
- Making it easy for people to donate and receive



Source: Annual Report on Kidney Transplantation 2019/20, NHS Blood and Transplant

LDKT Safety, Outcomes, Experience

UK TRANSPLANT REGISTRY Blood and Transplant

DONOR REPORTED OUTCOME MEASURES (DROMS) SURVEY

Please return data to ODT Hub: Information Services along with Kidney Living Donor Assessment Pre- and Post-Operative (FRM4190) form or Kidney Living Donor Assessment Follow-Up (FRM4191) form as appropriate.

ODT Hub: Information Services
NHS Blood and Transplant
Fox Den Road
Stoke Gifford
BRISTOL
BS34 8RR

Data will be collected at the following time points:
Pre-donation (on completion of work up), 1 year and 5 years post donation.

to help you understand more about your donation experience. Your information will be held by NHS Blood and Transplant in the UK Living Donor Registry to help monitor the wellbeing of kidney donors over time and what to expect.

Indicated) Section 2

1 is "very poor" and 10 is "excellent?"

here 1 is "almost all the time" and 10 is "as much as I expect?"

scale of 1-10 where 1 is "poor" and 10 is "great?"

ur family or social life on a scale of 1-10 where 1 is "significant effect"

ere 1 is "not at all" and 10 is "very positive?"

ur decision to donate, on a scale of 1-10 where 1 is "they think very"

ere 1 is "poor" and 10 is "excellent?"

image on a scale of 1-10 where 1 is "poor" and 10 is "excellent?"

ere 1 is "poor" and 10 is "excellent?"

activities such as working, housekeeping or travelling on a scale of

UK TRANSPLANT REGISTRY Blood and Transplant

DONOR REPORTED EXPERIENCE MEASURES (DREMS) SURVEY

Please return data to ODT Hub: Information Services along with Kidney Living Donor Assessment Follow-Up (FRM4191) form as appropriate. Data will be collected at 1 year post donation.

ODT Hub: Information Services
NHS Blood and Transplant
Fox Den Road
Stoke Gifford
BRISTOL
BS34 8RR

Dear Donor,

We would be grateful if you could complete this short survey to help us understand more about your donation experience. Your information will be held by NHS Blood and Transplant in the UK Living Donor Registry to help monitor the wellbeing of kidney donors over time and also inform people who are considering donating a kidney about what to expect.

Thank you for your support.

ACCESSING THE LIVING DONOR PROGRAMME (Please answer all questions unless indicated) Section 2

- How easy was it to find out about living donation?
Please circle: Not at all 1 - 2 - 3 - 4
- How easy was it for you to make contact with the transplant team?
Please circle: Not at all 1 - 2 - 3 - 4
- How would you rate the speed of response from the transplant team?
Please circle: Very poor 1 - 2 - 3 - 4
- How welcoming was the response to you?
Please circle: Not at all 1 - 2 - 3 - 4

FRM5385/1 (Donor Reported Experience Measures)

Section 3

ordinators?
8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

donation team?
8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

assessment process?
to help you understand the process and the timeframes involved?
6 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

not the assessment process?
5 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

5 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

assessment?
6 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

part of your assessment?
6 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

8 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

updated through the process?
5 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

ing assessment?
5 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

information provided to you?

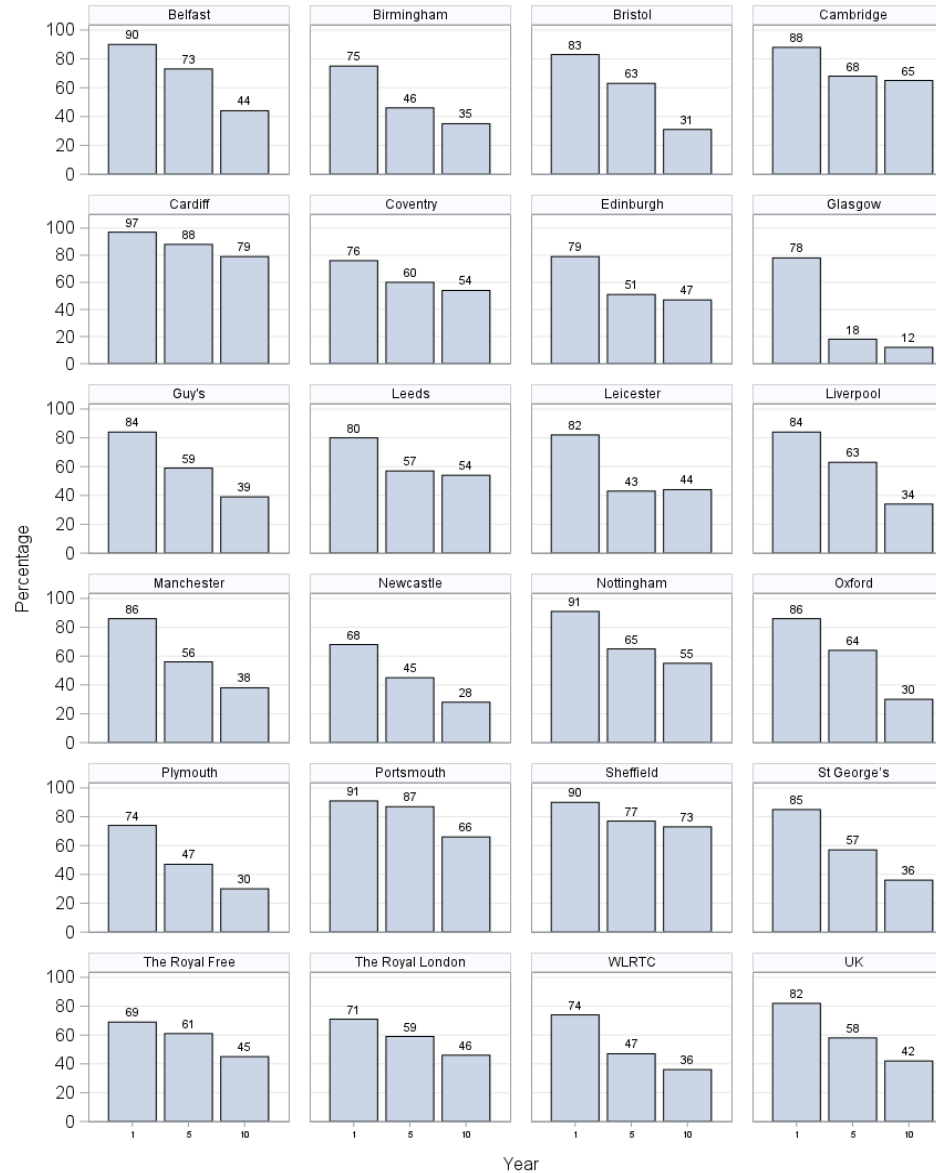
- 20 point questionnaire
- Self-reported **outcomes**
- Collected in UK Living Donor Registry
 - **Pre-donation:** once assessment complete
 - **Post donation:** 1 & 5 years

- Self-reported **experience**
 - **Assessment**
 - **Hospital stay**
 - **After donation**
- Collected in UK Living Donor Registry
 - **Post donation:** 1 year anniversary

Donor Follow-up by Centre

➤ 1, 5, & 10 years

Figure 6.5 Percentage of donors with lifetime follow-up reported, by centre





Living Donation Digital Transformation

UKLKSS

Donor registration

Donor follow-up

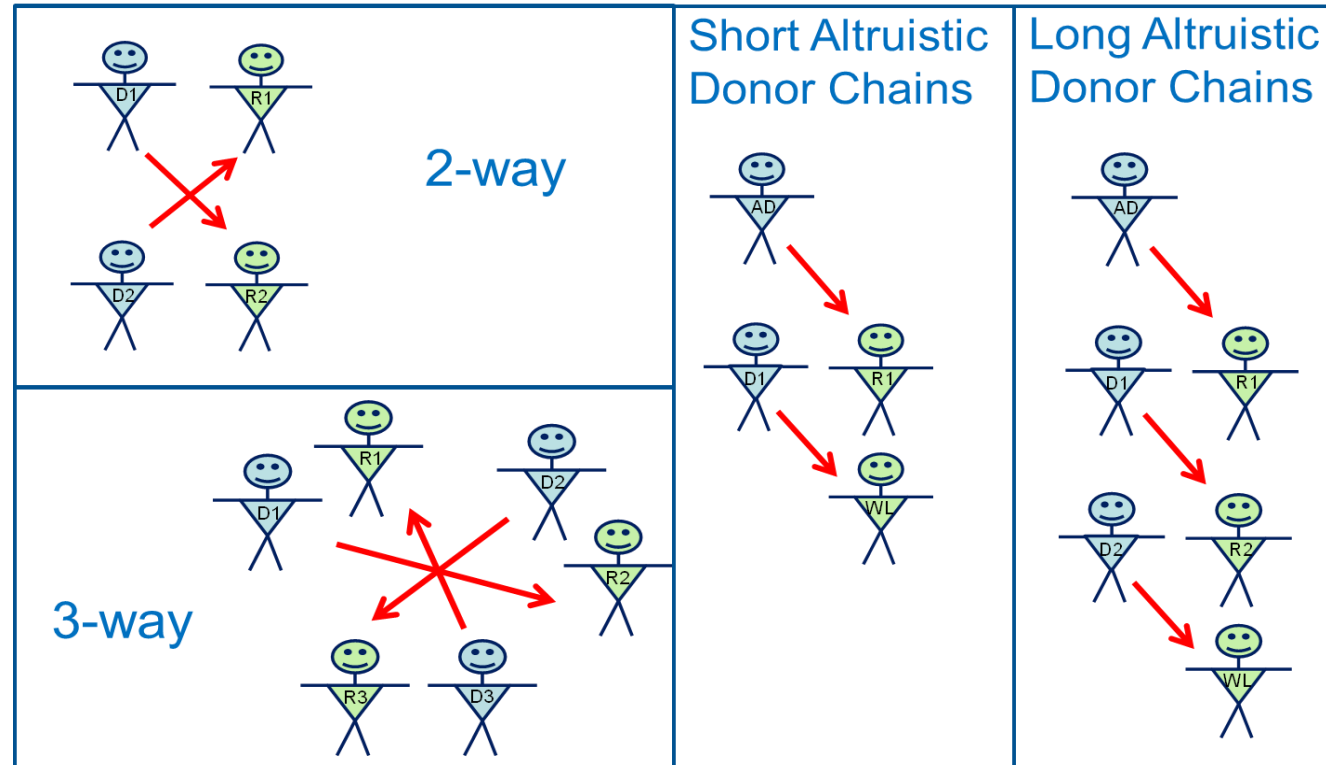
Self-reported measures



Living Donation Digital Transformation

- To underpin the 'end to end' living donor transplantation pathway
 - Registration to life-long follow-up
 - In 3 phases
- Meet strategic objectives
- Remove paper forms and manual processes
- Improve completeness and accuracy of data collection and reporting
- Facilitate donor and recipient self-reporting
- Minimise risk and maximise potential of the UK living kidney sharing scheme

Phase 1



- Remove paper forms and manual processes in the UKLKSS
- Minimise risk



Living Donation Digital Transformation

- Business Requirements Specification and Strategic Business Case in progress
- External user group
 - Sarah Lundie, Lisa Silas, Aisling Courtney, Frank Dor, Keith Graetz, Tracey Rees, Jeanette Ayres, John Asher, Derek Manas
- Implementation for phase 1 planned for 2021/22 (funding dependent)

The UK LKD Network

UK LKD Network

- Established October 2017; 3rd Annual Meeting
- In the next year
 - Embed in future plans: UK Strategy, GIRFT, KQuIP
 - Review Terms of Reference
 - Leadership succession planning: Chair and RA Representation
 - Funding arrangements
- Expressions of interest to
 - Network Chair: caroline.wroe@nhs.net; lisa.Burnapp@nhsbt.nhs.uk
 - RA Representation: katie.vinen@nhs.net

Saying Thank You....

Saying 'Thank You' to Living Donors

- Fixed Time Working Group
 - Representation from living donors, recipients, coordinators, NHSBT
- Aim to create on-line resources to support recipients of anonymous living donations to say 'Thank you'
 - Team 'Thank you' (Sheffield 'Daisy Chain' initiative)
 - Recipient to donor 'Thank you'
- Deliver by Spring 2021



Now....

- The only way is up
- We have some exciting opportunities
 - Learning from COVID
 - New Strategy
 - GIRFT



Thank you.

Everyone

